

Family Satisfaction in the ICU (FS-ICU) Survey: Coding Key Manual for 34 Variable Names

We would like your opinions about your loved one's recent admission to the Intensive Care Unit (ICU)

Your loved one was a patient in the ICU at [name of hospital]. The questions that follow ask **YOU** about your loved one's **most recent ICU admission**. We understand that there were probably many doctors and nurses and other staff involved in caring for your loved one. We know that there may be exceptions, but we are interested in your overall assessment of the quality of care we delivered. We understand that this was probably a very difficult time for you and your loved ones. We would appreciate you taking the time to provide us with your opinion.

PART 1: SATISFACTION WITH CARE

Please check one box that best reflects your views. If the question does not apply to your loved one's stay, then check "N/A" for not applicable.

HOW DID WE TREAT YOUR LOVED ONE? *(Please check one box for each item)*

- | | | | | | | | |
|---------|---|---|---|------------------------------------|------------------------------------|------------------------------------|-----------------------------------|
| 1. | Concern and Caring by ICU Staff:
The courtesy, respect and compassion your loved one (the patient) was given | <input type="checkbox"/> 1
Excellent | <input type="checkbox"/> 2
Very Good | <input type="checkbox"/> 3
Good | <input type="checkbox"/> 4
Fair | <input type="checkbox"/> 5
Poor | <input type="checkbox"/> 6
N/A |
| fscarep | | | | | | | |
| 2. | Symptom Management:
How well the ICU staff assessed and treated your loved one's symptoms | | | | | | |
| fspain | Pain | <input type="checkbox"/> 1
Excellent | <input type="checkbox"/> 2
Very Good | <input type="checkbox"/> 3
Good | <input type="checkbox"/> 4
Fair | <input type="checkbox"/> 5
Poor | <input type="checkbox"/> 6
N/A |
| fsbreat | Breathlessness | <input type="checkbox"/> 1
Excellent | <input type="checkbox"/> 2
Very Good | <input type="checkbox"/> 3
Good | <input type="checkbox"/> 4
Fair | <input type="checkbox"/> 5
Poor | <input type="checkbox"/> 6
N/A |
| fsagit | Agitation | <input type="checkbox"/> 1
Excellent | <input type="checkbox"/> 2
Very Good | <input type="checkbox"/> 3
Good | <input type="checkbox"/> 4
Fair | <input type="checkbox"/> 5
Poor | <input type="checkbox"/> 6
N/A |

HOW DID WE TREAT YOU? (Please check one box for each item)

3.	Consideration of your needs:	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
fsneeds	How well the ICU staff showed an interest in your needs	Excellent	Very Good	Good	Fair	Poor	N/A
4.	Emotional support:	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
fsemot	How well the ICU staff provided emotional support	Excellent	Very Good	Good	Fair	Poor	N/A
5.	Spiritual Support:	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
fsspir	How well the ICU staff met your spiritual/religious needs	Excellent	Very Good	Good	Fair	Poor	N/A
6.	Co-ordination of care:	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
fscoor	The teamwork of all the ICU staff who took care of your loved one	Excellent	Very Good	Good	Fair	Poor	N/A
7.	Concern and Caring by ICU Staff:	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
fscaref	The courtesy, respect and compassion <u>you</u> were given	Excellent	Very Good	Good	Fair	Poor	N/A

NURSES (Please check one box for each item)

8.	Skill and Competence of ICU Nurses:	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
fsrncare	How well the nurses cared for your loved one.	Excellent	Very Good	Good	Fair	Poor	N/A
9.	Frequency of Communication With ICU Nurses:	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
fsrncom	How often nurses communicated to you about your loved one's condition	Excellent	Very Good	Good	Fair	Poor	N/A

PHYSICIANS (All doctors, including residents)

(Please check one box for each item)

10. **Skill and Competence of ICU Doctors:** 1 2 3 4 5 6
 fsmdcare How well doctors cared for your loved one. Excellent Very Good Good Fair Poor N/A

11. **Frequency of Communication With ICU Doctors:** 1 2 3 4 5 6
 fsmdcom How often doctors communicated to you about your loved one's condition. Excellent Very Good Good Fair Poor N/A

Other ICU Staff

12. **Social work staff:** 1 2 3 4 5 6
 fsmsw How well the ICU social workers assisted and supported you. Excellent Very Good Good Fair Poor N/A

13. **Pastoral care staff:** 1 2 3 4 5 6
 fschapl How well the ICU chaplain assisted and supported you. Excellent Very Good Good Fair Poor N/A

THE ICU *(Please check one box for each item)*

14. **Atmosphere of ICU was . . . ?** 1 2 3 4 5 6
 fsicuatm Excellent Very Good Good Fair Poor N/A

THE WAITING ROOM *(Please check one box for each item)*

15. **Atmosphere in the ICU Waiting Room was . . . ?** 1 2 3 4 5 6
 fsicuwrr Excellent Very Good Good Fair Poor N/A

LOOKING BACK ON THE CARE YOUR LOVED ONE AND YOU RECEIVED

(Please check one box for each item)

16. **Overall satisfaction with your experience in the ICU** 1 2 3 4 5
 fsicusat Completely Satisfied Very Satisfied Mostly Satisfied Slightly Dissatisfied Very Dissatisfied

**PART 2: FAMILY SATISFACTION WITH DECISION-MAKING
AROUND CARE OF CRITICALLY ILL PATIENTS**

This part of the questionnaire is designed to measure how you feel about your involvement in decisions related to your loved one's health care. In the Intensive Care Unit (ICU), your loved one may have received care from different people. We would like you to think about all the care your loved one received when you are answering the questions.

PLEASE CHECK ONE BOX THAT BEST DESCRIBES YOUR FEELINGS

INFORMATION NEEDS *(Please check one box for each item)*

- | | | | | | | | |
|----------|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 1. | Ease of getting information: | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| fsques | Willingness of ICU staff to answer your questions | Excellent | Very Good | Good | Fair | Poor | N/A |
| 2. | Understanding of Information: | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| fsexpl | How well ICU staff provided you with explanations that you understood | Excellent | Very Good | Good | Fair | Poor | N/A |
| 3. | Honesty of Information: | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| fshon | The honesty of information provided to you about your loved one's condition | Excellent | Very Good | Good | Fair | Poor | N/A |
| 4. | Completeness of Information: | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| fsinfo | How well ICU staff informed you what was happening to your loved one and why things were being done. | Excellent | Very Good | Good | Fair | Poor | N/A |
| 5. | Consistency of Information: | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| fsconsis | The consistency of information provided to you about your loved one's condition (i.e., Did you get a similar story from the doctor, nurse, etc.) | Excellent | Very Good | Good | Fair | Poor | N/A |

PROCESS OF MAKING DECISIONS:

During your loved one's stay in the ICU, many important decisions were made regarding the health care she or he received. From the following questions, pick one answer from each of the following set of ideas that best matches your views:

6. **Did you feel included in the decision making process?**

dmincl

- 1 I felt very excluded
- 2 I felt somewhat excluded
- 3 I felt neither included nor excluded from the decision making process
- 4 I felt somewhat included
- 5 I felt very included

7. **Were you involved at the right time in the decision making process?**

dmtime

- 1 I was involved far too late
- 2 I was involved a little too late
- 3 I was involved at the right time
- 4 I was involved a little too early
- 5 I was involved far too early

8. **Did you receive an appropriate amount of information to participate in the decision making process?**

dminfo

- 1 I received too much information
- 2 I received just enough information
- 3 I received too little information

9. **Did you feel you had enough time to think about the information provided?**

dmthink

- 1 I felt I could have used more time to think
- 2 I felt I had enough time to think
- 3 I felt that I had more than enough time to think

10. **Did you feel supported during the decision making process?**

dmsupp

- 1 I felt totally overwhelmed
- 2 I felt slightly overwhelmed
- 3 I felt neither overwhelmed nor supported
- 4 I felt supported
- 5 I felt very supported

11. **Did you feel you had control over the care of your loved one?**
dmcontrl
- 1 I felt really out of control and that the health care system took over and dictated the care my loved one received
 - 2 I felt somewhat out of control and that the health care system took over and dictated the care loved one received
 - 3 I felt neither in control or out of control
 - 4 I felt I had some control over the care my loved one received
 - 5 I felt that I had good control over the care my loved one received

12. **Were you given the right amount of hope that our loved one would recover?**
dmhope
- 1 I felt that I was not given any hope that my loved one would recover
 - 2 I felt that I was given too little hope that my loved one would recover
 - 3 I felt that I was given the right amount of hope that my loved one would recover
 - 4 I felt that I was given a bit too much hope that my loved one would recover
 - 5 I felt that I was given far too much hope that my loved one would recover

13. **Was there agreement within your family regarding the care that your loved one received?**
dmagree
- 1 I felt there were severe conflicts within my family
 - 2 I felt that there were some conflicts within my family
 - 3 I felt that there was neither conflict nor agreement in my family regarding the care my loved one received
 - 4 I felt that there was agreement in my family
 - 5 I felt there was strong agreement within my family

14. **When making decisions, did you have adequate time to have your concerns addressed and questions answered?**
dmansw
- 1 I could have used more time
 - 2 I had adequate time
 - 3 I had more than enough time

15. **Some people want everything done for their health problems while others do not want a lot done. How satisfied were you with the LEVEL or amount of health care your loved one received in the ICU?**

dmdone

- | | | | | |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| Very
Dissatisfied | Slightly
Dissatisfied | Mostly
Satisfied | Very
Satisfied | Completely
Satisfied |

16. Overall satisfaction with your role in the decision-making related to the care of your loved one in the ICU.

- dmsatisf 1 2 3 4 5
- Very Slightly Mostly Very Completely
Dissatisfied Dissatisfied Satisfied Satisfied Satisfied

If your loved one died during the ICU stay, please answer the following questions. If your loved one did not die please skip to question 20.

17. Which of the following best describes your views:

- 1 I felt my loved one's life was prolonged unnecessarily
- 2 I felt my loved one's life was slightly prolonged unnecessarily
- 3 I felt my loved one's life was neither prolonged nor shortened unnecessarily
- 4 I felt my loved one's life was slightly shortened unnecessarily
- 5 I felt my loved one's life was shortened unnecessarily

18. During the final hours of your loved one's life, which of the following best describes your views:

- 1 I felt that he/she was very uncomfortable
- 2 I felt that he/she was slightly uncomfortable
- 3 I felt that he/she was mostly comfortable
- 4 I felt that he/she was very comfortable
- 5 I felt that he/she was totally comfortable

19. During the last few hours before my loved one's death, which of the following best describes your views:

- 1 I felt very abandoned by the health care team
- 2 I felt abandoned by the health care team
- 3 I felt neither abandoned nor supported by the health care team
- 4 I felt supported by the health care team
- 5 I felt very supported by the health care team

20. Do you have any suggestions on how to make care provided in the ICU better?

21. Do you have any comments on things we did well?

22. Please add any comments or suggestions that you feel may be helpful to the staff.

We would like to thank you very much for your participation and your opinions.